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## REVIEW

# Ethics roundtable: 'Open-ended ICU care: Can we afford it?'

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### The case

The patient is a 27-year-old previously healthy male with a diagnosis of viral encephalitis with a lymphocytic pleocytosis on cerebrospinal fluid examination. For 3 months, he has been in status epilepticus (SE) on high doses of barbiturates, benzodiazepines, and ketamine and a ketogenic feeding-tube formula. He remains in burst suppression on continuous electroencephalography (EEG). He is trached and has a percutaneous endoscopic gastrostomy (PEG) feeding tube. He has been treated several times for pneumonia, and he is on a warming blanket and is on vasopressors to maintain his blood pressure. His vitals are stable and his lab work is within limits. The sedation is decreased under EEG guidance every 72 hours, after which he goes back into SE and heavy sedation is resumed. The latest magnetic resonance imaging (MRI) shows edema but otherwise no obvious permanent cortical damage. The family wants a realistic assessment of the likely outcome. The neurologist tells them the literature suggests the outlook is poor but not 100% fatal. As long as all of his other organs are functioning on life support, there is always a chance the seizures will stop at some time in the future, and so the neurologist recommends an open-ended intensive care unit (ICU) plan and hopes for that outcome.

### David Crippen

A fundamental tenet of legal justice is that it is better to let ten guilty men go free than convict one innocent man. The reciprocal in medicine is that it is better to artificially maintain life in ten death spirals than miss one expected survivor. Physicians are famous for ignoring impediments

to the care of their individual patients. No long-shot treatment is shelved and no expense is spared no matter how dim the potential outcome. A righteous contempt is shown toward administrative pleas to consider cost.

In the past, this strategy worked only as well as the ability of the resource allocation system providing for it: an open-ended credit card with an unclear path to replete funds. Now we are seeing strong evidence of a new health care allocation system that will create a closed system whereby excising some portions of the pie directly affects the size of the other portions. The bigger some portions get, the fewer are available.

The amount of money spent on end-of-life care, specifically dying at the end of life, dwarfs other expenditures. And the unique situation of critical care will create a double dip for each patient maintained on artificial life support. If we are willing to maintain 100 moribund patients in ICUs for a prolonged period to yield one long-shot survivor, we do not pay for just the survivor. We pay also to warehouse the other 99 failures not quite dead or alive but with stable vital signs.

Since it is difficult to know on admission which patients will benefit from life-supporting organ failure reversal, we admit all comers for a trial. Now comes a logical extension of that policy. At any time in the course of treatment, it is equally difficult to predict outcome, so we should maintain most if not all moribund patients indefinitely to avoid killing the occasional unexpectedly survivor.

In the case presented here, we have a long-term ICU patient with a small but potentially survivable prognosis on a seemingly endless course of life support. Ten years ago, most physicians would have buckled down and maintained such a patient simply until he died of something else. As in a poker game, the winning card was still in the deck but could appear at any time.

Physicians are looking at anecdotal evidence that we should wait longer before declaring unsalvageability, but we are facing health care reform that will expect physicians to care for more patients more cheaply. That pie can be cut only so many ways. Every day a long-term patient lies in an ICU is a day that resources for other patients diminish commensurately. How long is long

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enough? How long is too long? How many moribund patients are we willing to warehouse to find one outlier? The question then becomes how will our intrepid concern for our individual patients be affected by real-time competition for others desiring their pieces of the pie?

### **Dick Burrows**

Can we afford open-ended ICU care? No, the resources are inadequate.

There can be no argument that improved technology has revolutionized medical treatment. There is improved survival in many conditions that previously would have been fatal.

The downside is an assumption that a technical (ICU) solution can solve an adaptive sociocultural problem [1]; death and dying are not the result of a failure of technology. So far, death remains undefeated [2], resulting in questionable costs that are greatest in the last few weeks of life. Death occurs in 100% of people, but dying is a process, and the exact time of death is seldom definable, making individual decisions to stop resuscitation extremely difficult, especially in cases in which technology has delayed death, and there are always those who 'beat the odds'. The failure of medical school curricula to address the topic of death and dying [2] means that clinicians are ill equipped to deal with the subject. The pressure to apply the technology, irrespectively of costs, is considerable.

Medicine has changed to accommodate the cost of the technology. The days in which the patient approached the doctor and paid for the service (when the patient could) are long gone. A third party, either the state or insurance of some sort, has taken responsibility for payment, but the relationship is complex, and ultimately the individual or (more likely) the family remains responsible for medical care. This is reflected in the fact that 62% of bankruptcies in the US are for medical reasons [3].

As a result, the right of the physician to treat as he or she sees fit has been curtailed by the third party on the basis of the economic costs of treatment. It is difficult to ascertain the number of (adult) intensive care beds that should be provided for the population. One paper indicates six beds per 100,000 persons [4]. In 2004, in KwaZulu-Natal, South Africa, there was less than one ICU bed per 100,000 persons and this has not increased substantially. This meant that, in 2004, ICU clinicians at two hospitals in Durban denied entry to as many as half of the critically ill patients. The most common reason to refuse admission was that the unit was full. Another reason was that, in the view of the ICU staff, the admission would achieve no benefit to the patient. Consequently, the patient in the case above would not have been admitted. A mechanism did exist in some hospitals to refer patients as an interim measure to a

private unit but this was often curtailed for budget reasons. If a patient was insured, he or she would be admitted to a private hospital but a call to transfer him or her to the state sector would be inevitable when the insurance coverage was exhausted. At that time, the prognosis would be reviewed and a decision to admit or not to admit would be made.

The distinction between patient autonomy and economic issues is unclear as the clinician has a duty not to waste resources [5] and is forced to make decisions short of a point of certainty [6]. The availability of resources simply shifts that point away from certainty, and it serves no purpose to walk away from the problem, insisting that someone else deal with it.

In this part of the world (Ireland), the patient in the case above would be admitted, but the economic realities of the moment indicate that this will likely change precipitously over the coming months as there is a progressive failure to service demands. At some point, treatment will have to stop, the state will ration care, and the insurance company will limit coverage or initiate proceedings against the estate if treatment continues in the absence of continuing funds. Negotiation and conciliation will be the order of the day. It will be difficult.

### **Nino Stocchetti**

I think that the care plan in this case should be changed after 3 months or perhaps before. Three aspects should be considered:

1. The benefit for the patient. It looks very doubtful after such long treatment, and iatrogenic damage due to high-dose barbiturates and so on is obvious. My experience with high-dose barbiturates (7 to 8 g of pentothal per day in a 70-kg man) is that severe cardiac, hemodynamic, and infectious complications are the rule after the first days. I never used them for more than 7 to 10 days.
2. The benefit for the family. Family stress can reach unbearable levels in months of never-ending tension.
3. The benefit for society. My unit has 6 beds, 4 during summertime. This shortage and the costs related to every ICU bed make the responsible use of resources essential [7]. Keeping a highly specialized bed occupied for months denies this resource to others.

What makes this case especially difficult is the lack of strong evidence concerning the expected outcome. In traumatic brain injury, we base our prognosis on several thousands of cases [8], whereas for encephalitis, there is no database of comparable size. In fact, there is no large database at all. Anecdotal cases and even small series are of limited use, and different opinions and doubts are respectable.

However, an SE refractory to maximal treatment for 3 months indicates extremely severe brain damage and

does confirm that we do not have an effective treatment. Having confirmed the inefficacy of maximum treatment for 3 months, I would conclude that it is rather futile. Then the difficult choice is to justify a protracted unuseful treatment rather than its withdrawal.

Due to the admitted limited knowledge, I would ask colleagues from outside the department, with an international reputation, for a collegial expert opinion. If they confirmed my assessment, I would proceed; otherwise, I would wait further. Then I would offer the family the option of external consultation in order to dispel the notion that the reason the therapy plan is being pursued is that the treating doctors are bored or mistaken. The family has the right to call other experts.

Having collected the (presumed homogeneous) opinions of various colleagues (including, eventually, someone nominated by the family) about the futility of further insistence, I would talk again with the family, hoping to obtain their consensus. My proposal would be to stop barbiturates and ketamine, aiming at spontaneous breathing, not restarting high-dose sedation even if SE re-appeared. I would give the family the option of transferring the patient to another institution, if required.

### **Stephan A Mayer**

I would absolutely continue to offer long-term aggressive care and support to this patient. Tremendous and unexpected recoveries can happen only if you let them.

If there is one condition that can defy expectations and from which patients can emerge after months and months in coma, it is SE in a young patient with normal brain imaging and a clinical diagnosis of encephalitis. The literature, in fact, is replete with reports of similar patients recovering from coma after several months on pentobarbital.

One of our more memorable patients at Columbia [University, College of Physicians and Surgeons] was a Taiwanese woman in her early 20s with highly refractory SE whom we diagnosed with an ovarian teratoma and anti-NMDA-receptor antibodies and autoimmune encephalitis. It took several months to terminate the seizures, which came back relentlessly every time the pentobarbital was lifted, just like in the patient described above. Thereafter, she was in a seizure-free vegetative state for over 6 months. Finally, New York Presbyterian Hospital paid over \$100,000 for an air ambulance to fly her back to a hospital in Taiwan. It was that or provide a lifetime of care to an undocumented alien in a persistent vegetative state.

Imagine our shock when, 6 months later, the accepting neurologist sent us a photograph of her, smiling and apparently intact. It took a year for her to start to follow commands, then she entered rehabilitation, and now she has a second chance on life, with minimal disability. We

never in our wildest dreams expected her to recover after we sent her back to Taiwan. And she would never have had that chance if we had pushed the family to pull the plug when she was in our ICU.

Of course, patients have the right to be treated the way they want to and that includes the right to refuse unwanted life support. We all believe that, as physicians, we should not play God – it is not our role to make these decisions, and the patient has the final say. But the ideal of free will in medical decision-making is just that: an ideal. In real life, the decisions that family members make are a direct consequence of what they hear from us.

In the scenario above, I would provide a realistic estimate of the likely spectrum of outcomes in 1 year with continued full-court aggressive support. I would estimate that four possible outcomes have an equal likelihood of occurring: (a) dead of a fatal medical complication, (b) vegetative, (c) conscious and severely disabled, or (d) walking and talking and working on a good recovery. I would remind the family that as long as the goal is survival to discharge, our team would collectively focus on complete recovery as the goal of our efforts. Given that information, I then would provide three potential goals of action: (a) full medical support until discharge, (b) full medical support with a do-not-resuscitate (DNR) order, and (c) DNR and terminal extubation. These are the ‘three paths’, and they can pick only one path. I do not allow families (or ourselves) to pursue prolonged life support combined with ambivalent and half-hearted medical or neurological intervention.

Finally, I always give the family the option of changing the plan, cutting their losses, and opting for comfort at any point down the road if they feel that their loved one has been through enough. I call it our ‘money back guarantee’.

### **Peter Andrews**

This illustrative case has some unusual features that require further clarification. But the question ‘what management plan is in the best interests of this previously healthy young man, who is now requiring multiple-organ support for intractable SE and requiring barbiturate coma because of recurrent seizures?’ is important. I believe that the prognosis after 3 months on intractable SE as a complication of presumed viral encephalitis is poor in the extreme.

Before we can conclude that withdrawal of organ support is appropriate, a number of actions are required:

1. A multi-disciplinary team (MDT) discussion about this very difficult case should occur between neurology, critical care, neurophysiology, and infectious diseases. Possibly, a consult from a national expert on the encephalitis in question would also help establish the likely prognosis with more certainty. Neurophysiology

should be involved, monitoring the seizures on a daily basis.

2. The serum levels of anticonvulsants (those in addition to barbiturates) should be measured to establish that they are in their 'therapeutic range.' Commonly, phenytoin, sodium valproate, and levetiracetam [9] are used in these circumstances. Once these agents are optimized and after at least 24 hours of burst suppression induced by barbiturates, the anesthetic agent should be reduced. Recurrence of seizures (assessed by EEG and clinical exam and ideally with video EEG for both) mandates action to suppress this activity. This is the sequence of events described in this case.
3. After such a long period of seizures, it is likely that severe cerebral injury has occurred. However, I would consider the use of hypothermia to see whether this intervention could improve the situation [10]. There are reports of success in SE with this intervention.

After 3 months of intractable SE still requiring barbiturate-induced burst suppression, the outlook is very poor. Further MRI sequences may be helpful to document the extent of neurological damage (that is, diffusion-weighted imaging, diffusion tensor imaging, and so on). The neurologist has stated to the family that the outlook is poor but not 100% fatal. The literature that this prognosis is based upon is likely to come from papers relating to the particular viral encephalitis. I would suggest, however, that when the situation is complicated by such a long period of SE, the outlook is considerably worse.

If the patient were comatose but not in SE and not requiring advanced organ support, I would recommend discharge to an acute neurology ward with a tracheostomy and PEG or RIG (radiologically inserted gastrostomy) feeding. The situation could then be monitored over a number of weeks or months. However, in this case, the MDT should agree on this prognosis and then meet with the family to discuss changing the emphasis of care to palliation and comfort care.

### Tom Bleck

The data available from studies of SE in the literature really provide no guidance in dealing with a case such as this. There are published cases of recovery after long durations of SE refractory to treatments other than suppression by barbiturates (weeks to months), but there are no population-based or even hospital-based analyses with denominators to provide an estimate of the likelihood of functional recovery. My practice in this circumstance is to pay attention to the MRI results; if the MRI does not show evidence of progressive tissue destruction, then I continue to support the patients aggressively. I am aware of several patients who were in SE suppressed with high-dose barbiturates for over

3 months and who eventually awakened and returned to reasonably normal function. In my experience, about 1 patient out of 5 in this patient's circumstances returns to work or school after prolonged treatment for refractory SE and almost all of the remainder die in the ICU. So I agree with the neurologist in this case.

In the absence of demonstrated brain destruction, withdrawing aggressive therapy for SE because the staff or family is exhausted by the strain of prolonged treatment would likely result in another example of self-fulfilling prophecy. This phenomenon is being recognized with increasing frequency in neurocritical care. As a resident, I was trained to appear wise by hanging crepe and counseling an early transition to comfort care. As I get older, I sometimes ponder how many potentially functional survivors I consigned to an early grave. This is an area that cries out for a multi-center outcome analysis based on quality of life-years.

How was this patient's diagnosis of 'viral' encephalitis established? In the absence of virologic or serologic confirmation, one should consider an autoimmune etiology and perhaps treat with immunosuppressive agents or plasma exchange after an appropriate workup. There are other treatment modalities, including electroconvulsive therapy, cooling, or vagal nerve or deep brain stimulation, to be considered. If the seizures arise from a consistent focus, resective surgery or multiple subpial transection could also be considered.

### Leslie Whetstone

#### Conclusions

This case highlights, among other things, the remarkable differences in health care resource allocation throughout the world. Both Bleck and Mayer, neurologists practicing in the US, are reluctant to withdraw an enormous expenditure of time and resources if there is a marginal chance for survival [11]. Both conclude that there are insufficient data to accurately prognosticate long-term outcome and so continuing open-ended aggressive treatment is appropriate. Their approach contrasts markedly with that of Burrows and Stocchetti, intensivists practicing in Europe. Both Burrows and Stocchetti must consider the investment of time and resources because expending resources on one patient impacts the care of others. While the Americans do not discuss the issue of cost as a determinant factor in their analyses, the Europeans clearly regard it as a key component to the issue.

Andrews does not address cost but instead recommends an MDT approach to assess the patient as well as additional tests and therapies to ensure that all possibilities for improvement have been exhausted. He concludes that if such an alternative care plan showed no further change, intractable SE described in the clinical scenario would indicate moving to a palliative care plan.



Crippen, an American with a utilitarian mindset, unveils the iniquities inherent in a private practice system by asking difficult questions that run contrary to American sensibilities. Although he does not go so far as to invoke the concept of rationing as prioritization, it is the logical conclusion to his argument.

This case illustrates the need for resource allocation policies at the macro level. Before this can be done, however, established guidelines that are grounded in evidence-based medicine are necessary. Otherwise, the inflammatory rhetoric commonly heard in the current health care reform debate in the US (that government or some other regulatory body will be 'killing grandma') will paralyze discussion. Moreover, it is worth noting that Burrows and Stocchetti are not individual physicians flouting the rules; they are acting within constraints that their countries have implemented. Mayer and Bleck cannot be expected to ameliorate the shortcomings of an unfair and moribund system on their own.

Ethically, this case emphasizes the need for taking resource allocation policies to a level away from individuals making isolated anecdotal decisions at the bedside. Taking the debate to a level of authoritative data erases the potential for capricious decision making. Once those data are transparently obtained, a rational discussion as to what level is appropriate to stop treatment can proceed.

The public needs assurance that they are not deprived of treatment based on an arbitrary or mercenary economic model. Within the past 6 months, an authoritative figure, Sanjay Gupta, published a book [12] that chronicled recovery from near death; a patient diagnosed in persistent vegetative state is now allegedly using assistive communication devices, and a poorly managed recommendation regarding mammogram protocols reinforced societal disdain for bureaucratic regulation. These cases as well as the one presented here should be viewed through the lens of objective data rather than the bias of individual physicians [13]. When this occurs, the care of these patients will be standardized for the most benefit, the most reasonable cost, and the most equity for all.

#### Abbreviations

DNR, do not resuscitate; EEG, electroencephalography; ICU, intensive care unit; MDT, multi-disciplinary team; MRI, magnetic resonance imaging; PEG, percutaneous endoscopic gastrostomy; SE, status epilepticus.

#### Competing interests

The authors declare that they have no competing interests.

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